

Bill 5450

John Watkins

If you have a brain, it's possible you might experience a seizure within your lifetime. But some have to live with this throughout their lifetime, and some suffer more severely than others. 1 of every 26 Americans will develop epilepsy within their lifetime. An estimated 3 million Americans and 65 million people worldwide currently live with epilepsy and 200,000 are being diagnosed with epilepsy each year. In 2/3 of the cases the cause is unknown. This condition affects more people than Muscular Dystrophy, Parkinson's Disease, and Multiple Sclerosis combined. There are 50,000 deaths each year in the U.S. from prolonged seizures (Epilepticus) or Sudden Unexpected Death in Epilepsy (SUDEP), which accounts for 34% of all deaths in children. But somehow the research receives less federal funding per patient than those with Muscular Dystrophy, Parkinson's Disease, and Multiple Sclerosis. Epilepsy costs the United States approximately \$15.5 billion each year. The indirect costs associated with uncontrolled seizures are seven times higher than that of the average for all chronic diseases.

Now wait a minute... Here's where it gets worse. In extreme cases of epilepsy, conditions like Cortical Dysphasia or Dravet Syndrome cause the person to experience seizures 80+ times per day. In many of these cases the person who suffers is treatment-resistant. Parents of epileptic children find themselves faced with trying dietary changes, drug trials, and even surgeries to alleviate the seizures. To avoid surgery, combinations of seizure medications are applied. The combined impact of multiple seizures and medication side effects can significantly impact the quality of life for both the children and their caregivers. The families of Epileptics with uncontrollable seizures tow a heavy line. Some lose their job because their child requires chronic care and for some it may seem like there is no light at the end of the tunnel. But for some of those people that have exhausted all medical options have found hope for seizure relief through the Cannabis plant.

Strains like Charlotte's Web and Harley Quinn have surfaced. High CBD / Low THC strains have been helping epileptics and are finding success. It was last reported that 115 families from 43 states have moved to Colorado to gain access to the plant for their children. These are just the ones who managed to stay. They left their families, friends, jobs, and homes for the purpose of obtaining special high CBD strains of Cannabis that had reportedly stop seizures in some children in CO. Dr. Margaret Gedde of Colorado Springs treats 195 pediatric cases that are using Cannabis oil to treat seizures. With this group of children there has been a documented 78% success rate. "This is what is called anecdotal evidence,

but it is also very real," said Gedde, "We have 78 percent of patients benefiting from this. Often it allows them to get off more dangerous medications. Clearly it has a role in treating epilepsy." The remaining patients either stopped using the oil because it made seizures worse, was ineffective, or because they moved back to a state where the oil is illegal and not obtainable.

Interestingly enough this has made the medical community take a closer at the science behind Cannabis and Epilepsy. The latest study being conducted is at New York University (NYU) under the direction of Dr. Orrin Devinsky. NYU is using Epidiolex (an extract from Cannabis Sativa), a 98% CBD and trace THC provided by GW Pharmaceuticals. They received an FDA approved phase 1 observational study. What this means is that there is no placebo being used in the study, therefore any evidence obtained during the observation will only be considered anecdotal. NYU will be monitoring seizure frequency to look for evidence of effectiveness along with office visits and follow-up communications with the patients. Dr. Devinsky stated "We hope that this study will pave the way for future further examining CBD as a therapeutic option, and ultimately offer a viable medication alternative in the future for patients suffering from seizure disorders." The study is monitoring 26 subjects but has received inquiries from more then 500 families and patients. The patients want and need access, even just to try...

Although NYU is not releasing any of the results of the current trial, I was able to meet one of the pediatric patients involved in the study. The child I had the pleasure of meeting was experiencing around 80-recorded seizures per day. But since being introduced to Epidiolex through NYU, he was only having 1 seizure per day (along with an increased appetite), with no other drugs in place. If this is just anecdotal evidence, I think most would accept it as long as the treatment is working and saving them or a loved one. I hope any and all others involved in the study experience the same successes and find and ability to be both drug and seizure free.

The Epilepsy Foundation has stepped up and has called on the DEA to implement a lesser drug schedule classification for Cannabis so it is more easily available for medical research. As it stands right now, The Federal Government has Cannabis listed as a Schedule 1 drug which is the same category as crack and heroin, defined as having no medical value and being highly addictive. The classification of cannabis as a Schedule 1 drug appears to be a point of contention within the government itself, as witnessed by its ownership of patent

number US6630507 B1. The Epilepsy Foundation supports changes in state laws to have access to Medical Cannabis as a treatment option for epilepsy, including pediatric use. The Epilepsy Foundation believes that an end to seizures should not be determined by one's zip code and stated "Our current situation as an epilepsy community is not acceptable. Families looking to access medical marijuana as a treatment are facing terrible decisions. One parent may move across the country to live with a child to seek this treatment. Other families may uproot entirely, including leaving their job, to move where they can access CBD oil. In the past, when therapies not yet approved by the Food and Drug Administration (FDA) were available abroad and left only to those who could afford to travel, we fought for compassionate access. We are here to continue the fight."

Should where you live determine what medical treatments you can receive? It really shouldn't, but it does and will continue to do so until more local and federal laws will reschedule Cannabis so more research can become available. Families are leaving behind everything for access to treatment options shown to be effective in the majority of patients. There is a need for more effective treatment for both children and adults living with Epilepsy. 1/3 of Epileptics still suffer from seizures despite their best efforts using medications, diet changes, and even surgery. It's time for sensible reform that will help restore a high quality of life to people who suffer from uncontrollable Epilepsy and reschedule Cannabis so further research can be done to help end the seizures. This is simply the right thing to do and it is the time for that change.